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ABSTRACT

The progress of a 4-year-old child with Rett Syndrome (a developmental disability resulting in severe mental and physical deficits in female children) in learning simple environmental control over an 18-month-period is described. A systematic program providing for contingency control of toys and music via switches was provided in the child's preschool classroom, and subsequently in other settings. The data showed that the ability to respond to environmental contingencies was retained despite the degeneration of other skills. Although hand use was promoted by the equipment, head responses were an even more effective response. (Author/DB)

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Fostering Environmental Control
In A Young Child With
Rett Syndrome: A Case Study

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Abstract

The progress of a four-year-old child with Rett Syndrome in learning simple environmental control over an 18-month period is described. A systematic program providing for contingency control of toys and music via switches was provided in the child's preschool classroom, and subsequently in other settings. The data show that the ability to respond to environmental contingencies is retained despite the degeneration of other skills. Although hand use was promoted, head responses were an even more effective response.

Rett Syndrome is a developmental disability resulting in severe mental and physical deficits in female children. First described less than thirty years ago, the syndrome results in progressive loss of cognitive and motor skills including speech and grasping. Skills are lost after apparently normal development in the first six to 18 months of life (Van Acker, 1991) although the assumption of early normalcy has been questioned recently as more data has become available on the early developmental histories of these children (Perry, 1991). The etiology of Rett Syndrome is as yet obscure and no cure is known. The syndrome is thought to afflict as many as 10,000 girls in the United States based on prevalence data in European studies, although only about 11% of this projected figure had been identified as of the mid-eighties (Moser & Naidu, 1986). The discrepancy is presumably due to the limited awareness of the syndrome within the clinical community.

One of the syndrome's unique and perhaps its most discriminative characteristic is the prevalence of stereotypic hand movements. These have been described as hand-wringing, or handwashing. They occur with very high frequency and may be accompanied by mouthing of the clasped hands or other forms of stereotyped hand action (Van Acker, 1991). Purposeful hand movements are lacking. Poor attention to objects and events in the physical environment has also been reported.

Clearly the lack of ability to reach and grasp objects voluntarily and poor attention to external stimuli afford the child with Rett Syndrome little opportunity to control objects in her environment. There have to date been some attempts to use adapted switches and toys or computer activities to motivate functional hand use

(Hanks, 1986), to motivate interest in the environment and to enhance awareness of cause and effect relations in the environment (Watson, Umansky, and Johnson, 1990; Wesecky, 1986; Zapella, 1986).

In this paper, we present data on the performance of a child with Rett syndrome in our Contingency Intervention program. Contingency Intervention is a data-based training program that seeks to improve the motivation of the young severely disabled child to attend and explore its environment. Switches and toys are used to promote learning and discrimination among various environmental contingencies, and to promote means-ends problem solving (Sullivan & Lewis, 1993). The program has successfully used switches, adapted toys and other stimulus devices to promote learning in disabled infants under 18 months of age and disabled preschool children who have limited opportunities to experience control of their environment (Brinker & Lewis, 1982a,b; Sullivan & Lewis, 1990; Sullivan & Lewis, 1993).

Our interest in the response of a child with Rett Syndrome to contingency intervention is both practical and theoretical. Because simple switch technology and the computer itself are becoming increasingly available as educational and therapeutic tools in special education and rehabilitation settings, it is important to inform the practitioner about the possible effectiveness of these tools given the severe disabilities associated with Rett Syndrome. However, the peculiar nature of the syndrome allows us to test whether the cognitive ability to detect and process information about environmental contingencies and to understand simple means-ends relations survives

despite the degeneration of CNS function.

The evidence suggests that detection of contingency information is so basic a human information processing skill that even young infants, who are as yet without coordinated manual skills will work to control stimuli contingent upon sucking, head-turns, footkicks and gross movements of the arm (Rovee-Collier, 1987; Lewis, Sullivan & Brooks-Gunn, 1985). Manual skills are not necessary. We have seen repeatedly in our work with disabled infants that despite motoric and cognitive deficits that the ability to master simple environmental contingencies is possible even in profoundly impaired infants. Such children may process contingency information more slowly, but the basic awareness that the environmental stimuli are correlated with one's behavior appears intact even when motor skills are extremely limited and apparent cognitive skills are at the 3-month level or less.

The level of cognitive function of the child with Rett Syndrome on standardized assessments has been recently reported to be uniformly less than 8 months with an average of 3 months on the Cattell Infant Intelligence Scale (Perry, Sarolo-McGarvey & Haddad, 1991). This level of cognitive function means that contingency play and exploration are developmentally appropriate skills which these children may still potentially possess. While contingency play centered on hand-activated switches might be successful in promoting adaptive hand use, it is also the case that other motor responses of the child apart from hand activity might provide additional opportunities for the child to learn to control events in the environment and lead to improved interest in and motivation to explore toys and other objects.

We had the opportunity to record data on the contingency learning activity of a child with Rett Syndrome, Vanessa¹, over the course of 18 months in her preschool class. This report describes Vanessa's success in learning two different contingencies, her attention, and some data on the generalization of skills.

METHOD

Vanessa is a severely disabled preschool-age child with a diagnosis of Rett's Syndrome. She became involved in the contingency intervention pilot teacher-training program as a student attending a regional day-training program in our state for severely and multiply handicapped children. She was one of several children in a class participating in a program to assist preschool teachers in state-operated facilities to incorporate adaptive toys and switches in their curriculum for the severely multiply-handicapped. She was 3.5 years old at the outset of our intervention.

Prior to our contact with her, Vanessa's history, abstracted from the record, is as follows. Vanessa was referred for early intervention services at 18 months by her pediatrician who was concerned about persisting delays in language and motor skills. Vanessa's ability to say a few words and to walk (albeit with a wide base and frequent falls) were subsequently lost. The diagnosis of Rett Syndrome was first considered at age 2 based upon the symptoms of hand-wringing, and decreased use of upper extremities. Rett Syndrome was eventually confirmed upon further neurological evaluation. Vanessa received early intervention services from throughout this period and attended regularly until age 3. Little progress was noted, however. At the time of

¹ Her name has been changed to protect her privacy.

preschool placement, cognitive, communicative and self-help skills were assessed in the 5 to 7 month range on various standardized assessments (Bayley, Reel, and Minnesota Scales, respectively). Gross and fine motor levels were somewhat higher (6-8 and 9-11 months, respectively).

Vanessa began attending the preschool day training program six months prior to our contact. At that time, the school record noted few social or adaptive behaviors. Screaming spells occurred regularly in home and at school. Her behavior was described as "autistic-like" and seizures were occurring regularly despite medication (valproic acid).

When observed by the investigators after some six months of the school program, screaming spells no longer occurred with any frequency and social responsivity had improved. Some eye contact was obtainable and Vanessa smiled occasionally in response to being spoken to. Seizures were still occurring and medication was in the process of being changed (valproic acid to carbamazepine).

When first observed by us, tone in her neck and trunk was low. Little and inconsistent interest in objects in the environment was reported and confirmed upon observation. There was no purposeful manipulation of objects or toys. Vanessa appeared to be in an exhausted/sleepy state much of the time. The strategy of the center staff was to work with her extensively when periods of alertness occurred.

Vanessa was selected by the teacher as a candidate for the contingency intervention program which supplemented the daily preschool/therapy regimen. The classroom teacher and aide had recently undergone training in the methods and

curriculum planning with the investigators. The teacher attempted to work with Vanessa in the manner proscribed at least weekly, health and other therapeutic and classroom activities permitting. Data from these sessions were recorded on a Laser-128 computer with a special interface. Initial training, ongoing monitoring of the data collection and periodic observations (every 2-3 months) of Vanessa were provided by the investigators. Vanessa participated in the contingency program for one year with an additional 3 months of in-home use.

The teacher and Vanessa's other therapists (speech, occupational, and physical) continued to include activities in her daily regimen which might augment a sense of environmental control and functional use of hands (e.g. attempts to promote finger feeding, for example). It was hoped that such activities in conjunction with the structured contingency training should serve to promote generalized expectations regarding controllable environmental events in the school setting.

Unless noted otherwise, Vanessa's contingency play/learning sessions were conducted while she was seated in her orthopedic chair with tray. A chest strap was used when poor tone in the trunk made it necessary for maintenance of an upright posture. Two switches, selected for ease of operation and positioned so that Vanessa's spontaneous movements could activate them, were always available. When training began, a press switch was placed behind her head and another, was placed on the tray, in midline within easy reach of her hands. Toys and other devices which served as the contingent consequence were positioned on a display shelf at the edge of her tray or on the tray itself. Musical toys and tapes were typically chosen because

both the teacher and her family reported that Vanessa enjoyed music and would attend to it. This is apparently a consistent finding with Rett syndrome (Wesecky, 1986). The specifics of switches, toys and their placement will be described in detail for each phase of the program.

The head switch was chosen as an initial contingent response in addition to the hand press because both report and observation indicated that Vanessa could pick her head up briefly and would often do so spontaneously. Promotion of head held upright was deemed to be an important educational goal, so that toys and other environmental objects might be attended. Also, the premise of contingency intervention is that the child must be taught to expect that environmental control is possible through a set of responses and their variation. Experience has taught us that an expectancy can often be more easily acquired using a head response if limb responses are unavailable or difficult for the child.

For the first session, a 3.5" diameter press pad (TASH, Markham, Ontario, CN) was mounted with Velcro to the high back of the chair, so that the back of the head would contact the switch when the head was held in an upright position. The switch was small enough so that displacement of the head from midline would cause the switch to be missed. On the tray, a 2.5 x 3.5" tread switch (Zygo Industries, Portland) was positioned in midline. Both switches produced an audible click when depressed, but the quality of the sound was discriminative, as was switch shape and texture. During a 3-minute baseline period, seated in this arrangement and with no contingent stimulation available, Vanessa averaged 3 head activations per minute and no hand

activations as a result of spontaneous activity.

For the first contingency training session, contact of either of these switches resulted in a discrete 3-sec. activation of a musical Television Toy² with a scrolling colorful picture. The musical TV was positioned on the end of the tray in midline of Vanessa's line of sight, provided that her head was upright. Based on the teacher's expectations for the child and the baseline, a goal of 4 or more head responses per minute and at least 1 hand press response per minute was set as the mastery criterion. In addition, contingency intervention methods require that criterion performance be documented in at least two consecutive sessions. Hand wringing, the classic symptom of the syndrome, was not specifically monitored in this study. However, handwringing responses were incompatible with hand presses and so were not reinforced.

RESULTS

The First Contingency Lesson. Figure 1a shows the responses per minute as recorded by the computer for the first contingency training session. There was a high rate of head activations (more than 20 per minute) in the first 2 minutes, followed by a decline, and then a resurgence of response. This rate of response to the introduction of a head press contingency was in excess of what had been observed when no contingent consequence was available for picking up the head (recall that baseline averaged 3 responses per minute). The child was never prompted to contact the switch during the session, verbally or physically. Secondly, although purposeful hand

² All toys used in the program were battery-adapted unless otherwise noted.

activity was described as being absent for this child, an observation confirmed during baseline, pressing activity on the tray-mounted switch occurred at low levels (1 to 6 presses across the 7-minute session). The total session length is consistent with what we have observed in other severely disabled children achieve in an initial session. The session might have been longer had not a seizure occurred, terminating the session.

These data confirmed that the physical positioning of the child, switches and choice of toy were appropriate, and the teacher's expectations of the child's ability to perform, given appropriate positioning and motivation, was perhaps too low. Based on the data, the program was modified so that maintaining a continuous head press response resulted in a prolonged consequence. In this way, sustained duration of head press responses was promoted. Also, a separate consequence was introduced for the hand press so as to provide more stimulus variety and the possibility of stimulus choice. The musical TV was continued for head presses while a plush mechanical pelican, which squawked and flapped its wings, became the contingent consequence for hand presses. These data are shown in Figure 1b. The figure shows hand press activity occurred in the same range as previously (1 - 8 responses per minute) and exhibited a habituation function. As can be seen, the rate of hand pressing declines from the first through the eighth minute, with an increase in the final minute. Head durations as expected were relatively brief. Rate of pressing also tended to decline over the first five minutes, but resurged during the last 3 minutes. Such declines over time are usually indicative of waning interest in the toy. In Vanessa's case, spontaneous recovery of responding seemed to occur.

Replications. Seven sessions were conducted subsequently over the ensuing 2-months. During these sessions, durations of head presses typically ranged from 2 to 12s per minute, but achieved 60s (i.e., the toy was activated continuously for the entire minute) in two sessions. Figure 2 tracks durations of head presses over several sessions: It shows the percentage of minutes in which head press was maintained for a minimum of 20 continuous seconds and the additional minutes in which the process was sustained for 60 sessions. Session length is given in parenthesis along the x-axis. The best performances occurred on 4/16 & 4/18 when continuous activations were sustained at asymptote for long periods. The figure also shows that sessions tended to be longer in length (14 minutes is usually the maximum attempted in our program). Use of hand switch also increased over this period, but more inconsistently. Figure 3 shows one such session, in which the maximum use of hand response occurred. Frequency of pressing by the hands is contrasted with frequency of pressing by head (Recall that head rates are expected to be low since the duration of head contacting the switch is being reinforced; hand responses receive only a brief access to the toy which is independent from the duration of that response, and so should be higher). The session is typical of the data in that hand responses tend to occur in bursts and attained as many as 10 responses per minute at maximum.

Retention of the Response. Following the sessions reported above, there was a break of approximately one month in the program, due to child illness and competing school events. Head press activity was either retained or recalled rather quickly when the program resumed. Figure 3 shows two sessions, the first after the

break and the fourth, approximately one month later. The session of 5/31 shows that maximum head presses occurred the first minute (15 seconds total duration), and at 8, 10 and 11 minutes (12-13 seconds total duration). Three peaks in hand press occurred during this session as well. These tended to occur during minutes when head presses were low, suggesting that Vanessa tended, for the most part, to alternate her activity and attention between the two contingencies. The session of 6/20 shows a fairly stable duration of head press (between 10 - 15s except for the first minute) with low, inconsistent use of the hand, marked by a response spike late in the session.

Responses to Novelty. When observing Vanessa on 7/1, the investigators instituted the following changes. First, in order to introduce novelty, a new consequence was provided for head presses. A tape of music that the child enjoyed at home was provided. The musical TV, which Vanessa continued to enjoy as evidenced by attention and some smiling, was now made contingent upon hand presses. The switch was taped to the toy itself, in an attempt to encourage manual contact of the object. Of the four sessions conducted in this manner, the head press response appeared to generalize to the new music, but hand presses actually fell off (Figure 4a). Figure 4a is a typical session from this month. It should be noted that the teacher reported that the child's typical state was "sleepy" throughout this month.

Since the musical TV had been used for some time now and the response to a novel stimulus had been promising, a new toy was introduced the following month. A musical drumming/whistling bear was made contingent on hand presses. Introduction

of this new toy for hand presses produced somewhat more hand responses. Use of the head press, for the taped music, fell off relative to earlier performance (Figure 4b). In subsequent session, the "Hand press for TV" contingency was reinstated, resulting in the same pattern of consistent but very low rates of hand presses. The head switch was used a great deal in this session, particularly in the early minutes and clear habituation of this response with the session is observed for the first time (Figure 4c).

Observation of Vanessa leads us to recommend a change to a switch with a larger surface area (5") and bright color (Big Red, Ablenet, Minneapolis). Since contact of the switch occurred in the absence of direct visual regard (the toy not the switch was typically attended), using a switch with these features might be more attention-getting and therefore more reinforcing for the child.

Change in the switch did appear to result in increased use of hand. Figure 5 shows a biphasic curve in which most contact of switch occurred in 1st minute followed by resurgence after the 6th minute. The toy was the same throughout. This type of response curve has in past work been associated with waning interest in the contingent outcome and is sometimes alleviated with the introduction of a novel contingent outcome within the session. For the next session, a criterion-based toy change after 6 minutes was instituted, if responses fell below 8 per minute. The introduction of a novel toy should lead to increased responding on one or both switches. To the extent that the child understands which response controls the outcome, the correct response will recover. Tape and musical TV were the two consequences. Head presses no longer resulted in any contingent outcome. Figure 6

shows the third of four sessions conducted in this manner. The greatest response on the round switch is seen in the first minute, with rapid decline thereafter. Head presses increase when arm responses have habituated and persist briefly when the novel toy was introduced. This pattern suggests that Vanessa spontaneously explored a previously functional response. Introduction of the change in toy (Panel B, after minute 6) resulted in some response recovery of hand press as well. The subsequent session essentially replicated this pattern.

These data suggest that a novel switch, and a change in contingent outcomes within a session led to lawful changes in hand use, although the best performances always occurred early in the session. Visual attention to the toy, especially when the musical TV was activated, was sustained, and on occasion, anticipatory. Hand response was observed to habituate and recover in patterns previously seen in other subjects with severe motor disabilities.

None of the hand presses were due to the stereotypic hand-wringing response. In Vanessa's case, hand-wringing occurred with hands held in midline, at about chest level, well above the switch mounted on the tray. Again, although this behavior was not monitored formally, we observed that when it did occur during the contingency session, it was usually during periods of inactivity on either switch. It seemed to serve a self-stimulatory role, for the most part. In the few sessions where they occurred with high frequency, the hand stereotypies seemed to 'short circuit' attempts to raise the hands to activate or touch the toy. It seemed better to position the switch lower than the toy it was to activate.

Other Effects. During the ninth month of the program, another development occurred. The teacher reported that Vanessa had begun to swat spontaneously at objects in the classroom play area, and would continue to do so if they produced a sound.

During the ensuing months, the program was continued with various toy changes and alternating use of the head and hand switch for control. Sessions were run less consistently because Vanessa was often sleepy and seizures were occurring with some frequency, although none was again observed during testing. Seizure medication was readjusted several times during this period. The quality of Vanessa's performance was uneven although some progress was noted. Positive emotional response to the program intensified at this time. In many sessions, Vanessa's excitement was clear and anticipatory as her chair was positioned for contingency activities. Smiling, laughter and occasional vocalizations were noted in the on-line record. Attempts to touch the toy were also observed. At the end of 12 months, Vanessa's teacher reported that Vanessa would play independently for short periods with a toy piano during table-time activities. For the next three months, the program of contingency activities was continued at home in the hope of promoting generalization to other settings. The teacher trained Vanessa's mother to set up and run the contingency activities. Eight sessions were logged at home in the 3-month period at irregular intervals on the intervention computer.

Final Follow-up. Approximately 15 months after we had begun working with her, Vanessa, now nearly 5 years old, was transferred to another classroom. When

observed in her new classroom, Vanessa was observed in an upright stander with a wide press plate (7x12", Kanor Toys, Hastings on Hudson, NY) and a toy, rotating musical bells, selected by her new teacher. A low rate of hand presses on the plate switch was observed over a 10-minute period. The teacher reported that this rate was typical for Vanessa since coming to this classroom. Vanessa's hand movements appeared purposeful during the session and no hand-wringing was observed. She was observed to hold one edge of the large plate switch, while pressing the opposite edge with the other, a strategy which may have helped inhibit the hand stereotypies. The move to a new classroom coincided with Vanessa's new IEP which included, for the first time, specific goals and objectives requiring not only switches for play but activities with self-initiated choice.

DISCUSSION

Our data suggest that this child with Rett Syndrome, despite developmental delay, degeneration and continued seizure activity, still retained the ability to detect and appropriately modify her behavior in response to environmental contingencies. Systematic exposure to opportunities for contingent control of audiovisual stimuli were positive, motivating experiences for the child, appeared to promote attention to toys and objects in the environment, and skills that apparently generalized to the larger classroom environment, the home and ultimately to a new classroom. Both head press and tray-mounted press switches were used by the child in a manner suggestive of learning and retention of each response, although response rates were greater, and more consistently demonstrated for the head press response.

Our findings, while limited, are encouraging. Collectively the data provide evidence that providing a child with Rett Syndrome with more than a single means to explore toys and other environmental stimuli is an intervention which is profitable to pursue. Although the increases in hand use were modest and inconsistent, they did appear to result, over the long-run, in generalized attempts to control toys in novel settings. Although the program was supposed to be administered only once weekly, it often occurred less frequently due to child absences, poor state and the priority given other therapeutic activities. Consequently, it must be admitted that our hypotheses were tested in less than ideal circumstances. Despite this, predictable and positive responses to the environment were promoted.

The rapid mastery of the head contingency even with this limited program suggests that this and other possible responses of the child be explored as an alternative to manual activity as a means of offering environmental control to the child. While manual responses are likely to be preferred and seem more "normal" to therapists and parents, any response which is voluntary on the part of the child and permits interaction with the environment will be a positive one in terms of promoting attention and interest on the part of the child. It is also desirable to allow the child two possible responses from the outset so that ultimately choices can be made by the child.

The incidence of hand-wringing was not monitored formally in this study either during the contingency sessions or during baseline periods. It was the case that in many of the sessions observed directly by us, little or no such activity occurred. In

others, it occurred as had been expected. This variability surprised us. Because we were neither punishing nor reinforcing hand responses, it was expected that they would occur at a fairly consistent rate over sessions and occur at rates similar to that seen in the classroom. This seemed not to be the case; in fact hand stereotypies appeared on the whole to occur less during contingency play, a finding also reported by Watson, et. al, 1990, who did monitor their occurrences. Stereotypes observed in many types of syndromes have been shown to vary with time, showing initial increases and ultimately decreases (Wehmeyer, 1991). Whether the variability we observed is due to this process, to sampling, to the nature of Rett Syndrome itself or to some distracting /inhibitory effect of contingency training is speculative at this point but bears further investigation.

Beyond of the therapeutic implications of these data, they do indeed advance the notion of detection and processing of environmental contingencies as a protected perceptual/cognitive function.

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Figure Captions

- Figure 1 Contingent activation of a musical scrolling television toy. Panel A (3/1) shows the first session in which a response on either press switch (head or hand) resulted in 3-second activation of the toy. Panel B (3/10) shows a subsequent session in which duration of pressing resulted in continuous activation of the toy.
- Figure 2 Percentage of session minutes during which head switch was continuously depressed. Black bars indicate the percentage of minutes that the response was sustained at least 20 secs. (30% of any single minute), hatched bars indicate the percentage of minutes that the response was sustained a full 60 seconds (asymptote). (Session lengths in minutes are shown in parenthesis.)
- Figure 3 Switch responses in two sessions showing peaks in hand response frequency (Panel A) and stabilization of head press duration (Panel B).
- Figure 4 Sessions showing variability in responding with the introduction of novel contingencies. Panel A shows increase in head response duration with introduction of new music, the familiar toy was contingent on hand responses. Panel B shows recovery of hand

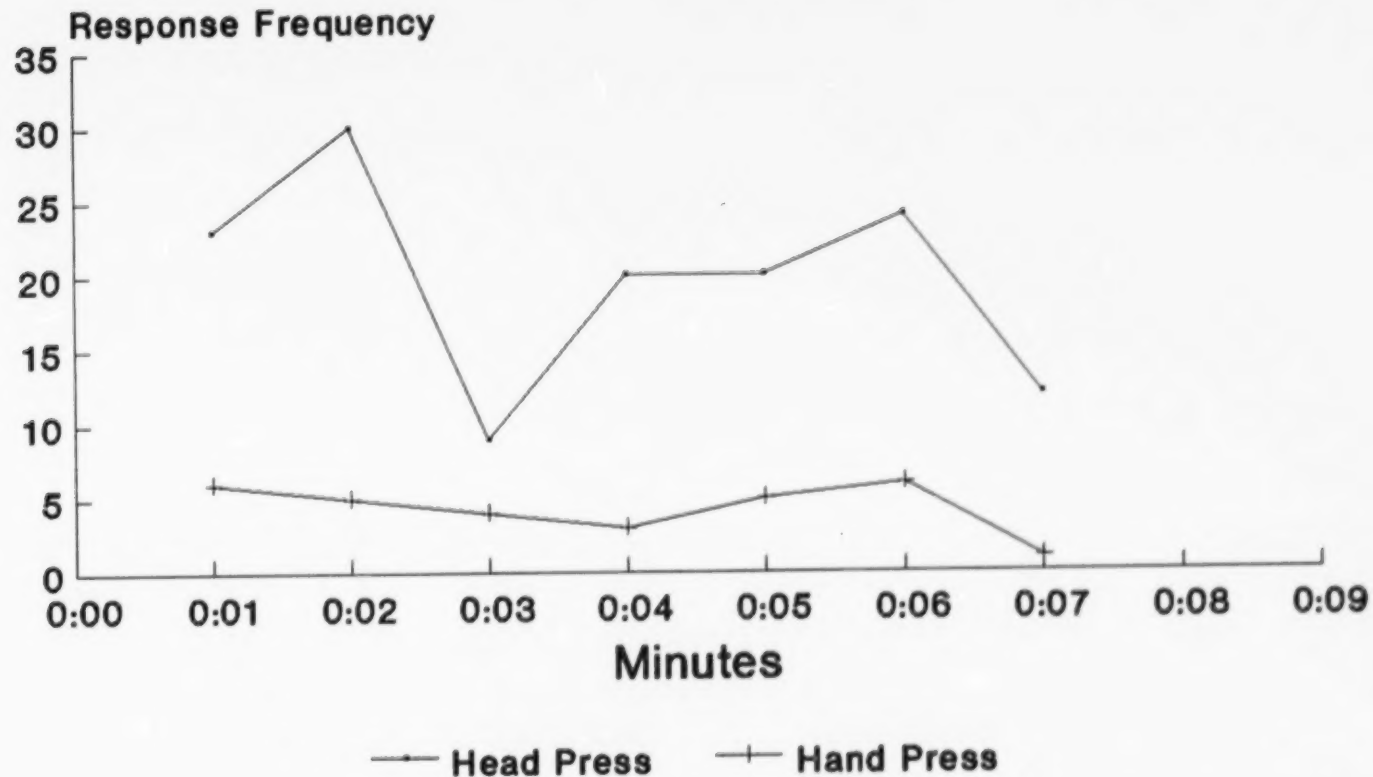
response with introduction of a new toy. Panel C show response to restoration of the familiar toy contingent hand presses.

Figure 5 Responses to the introductory of a novel switch.

Figure 6 Responses shown in response to a toy change. Panel A shows rapid habituation of hand responses controlling the familiar tape; Panel B shows the effect of a change of the control of the music box by the novel switch.

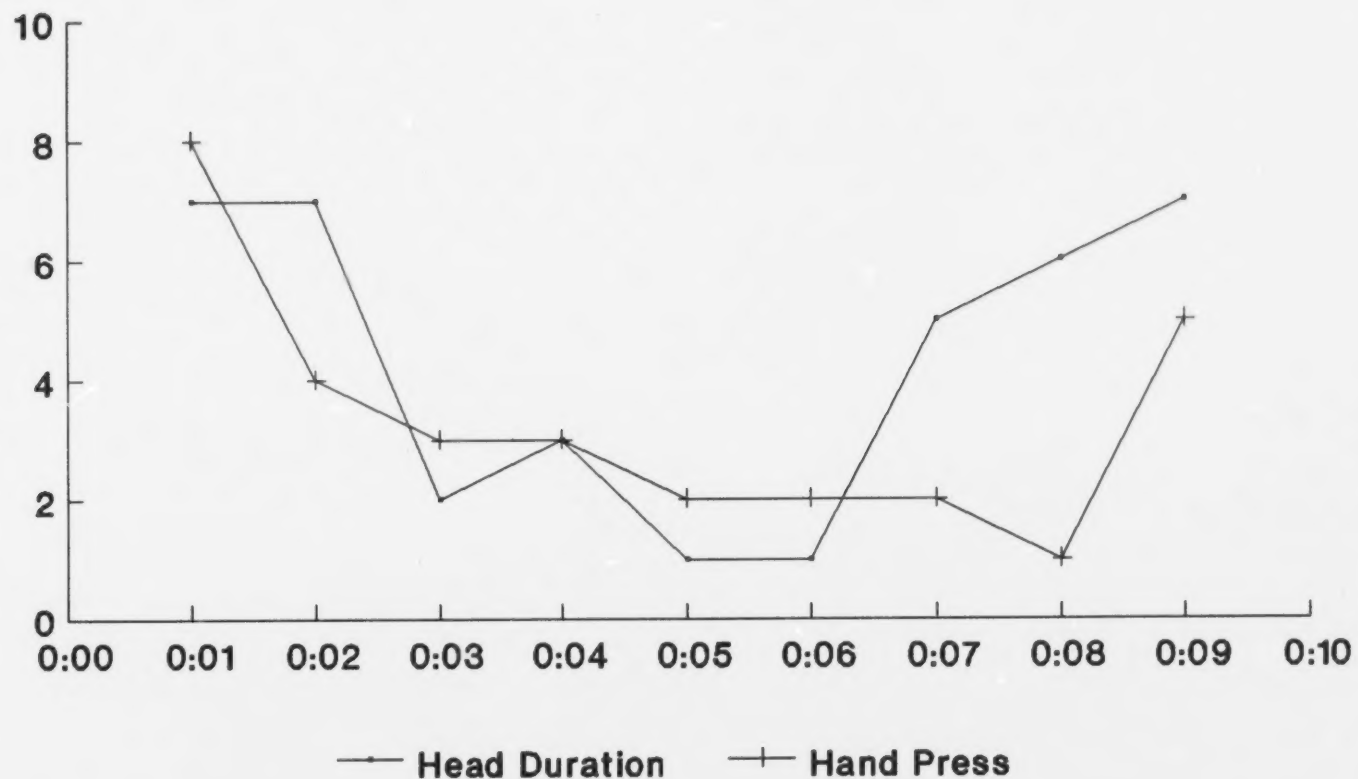
Head & Hand Contingencies 3/1

First Session

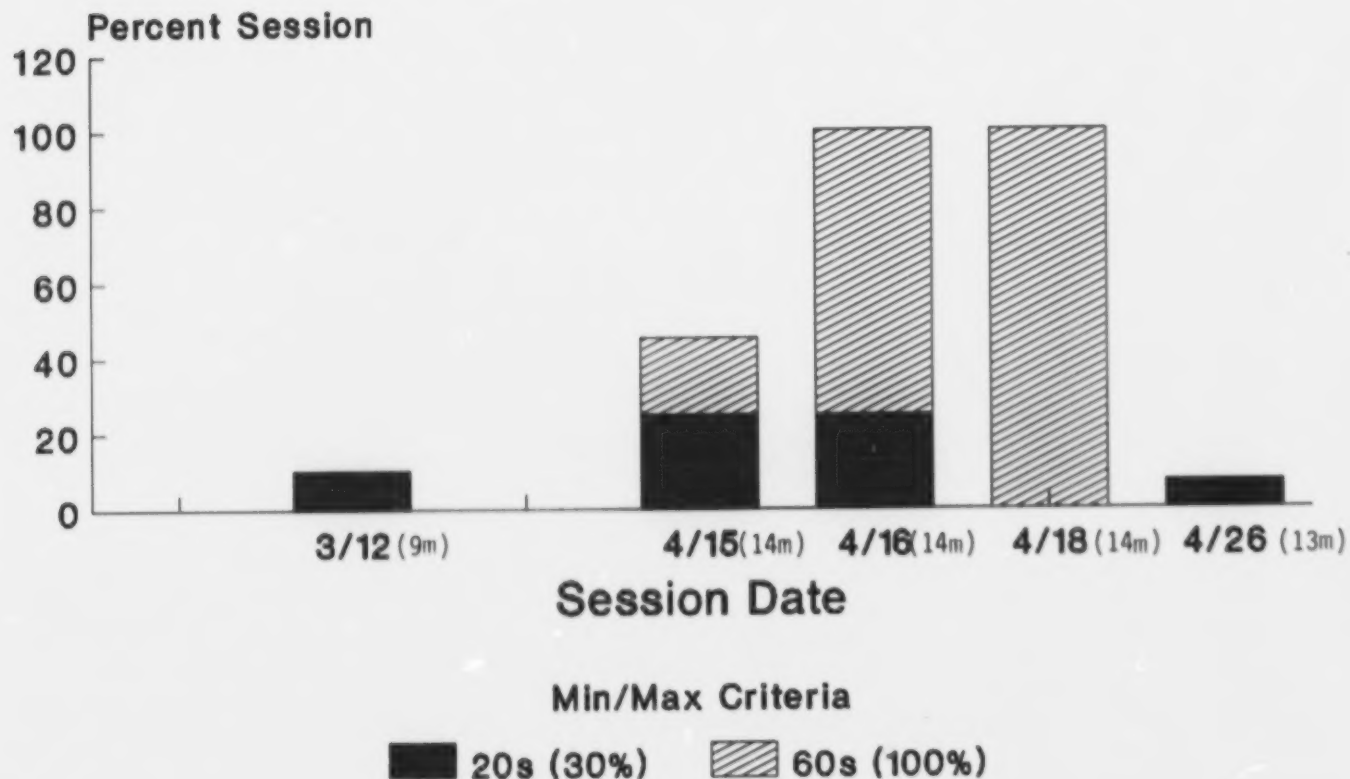


Head Continuous/MusicBox

Hand Press/Pelican 3/10

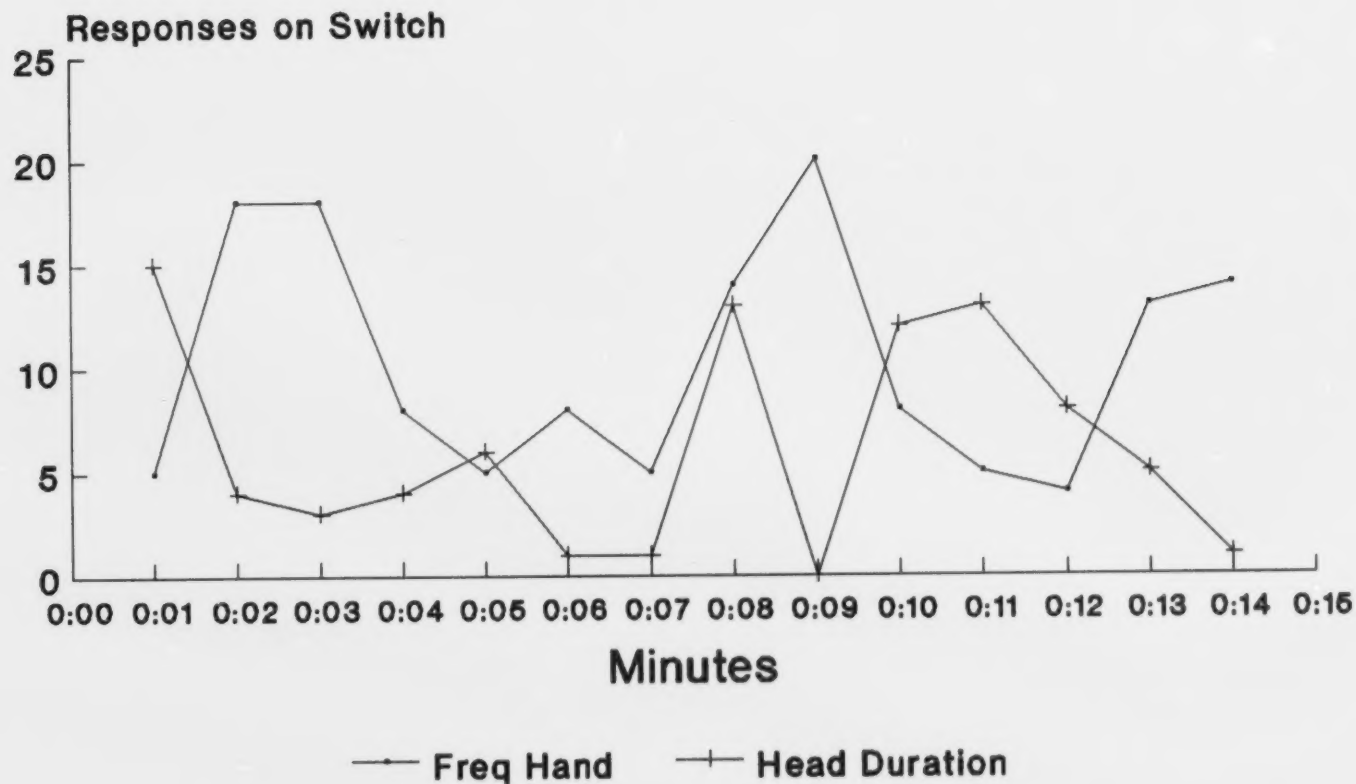


% Head Response Sustained (session lengths shown in parens)



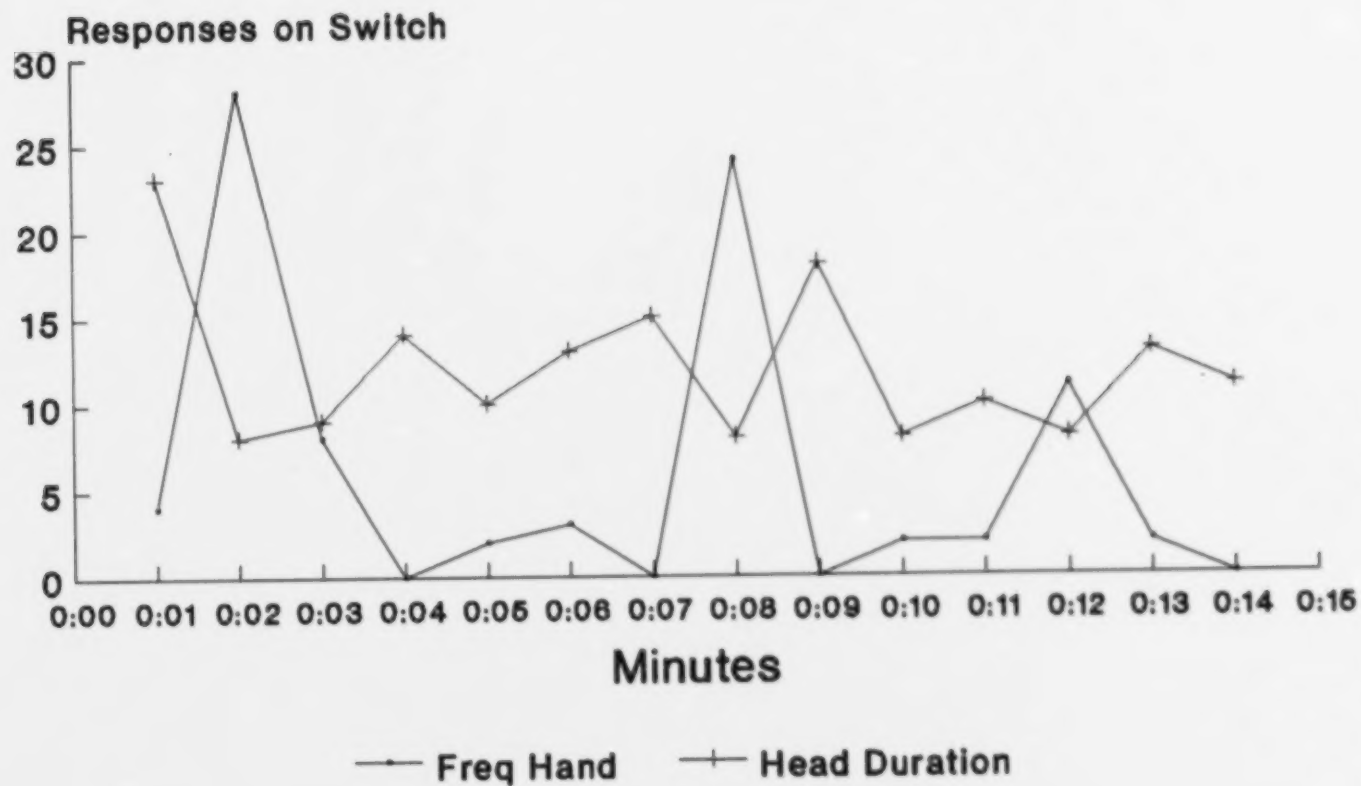
V Contingency Session 5/31

Press



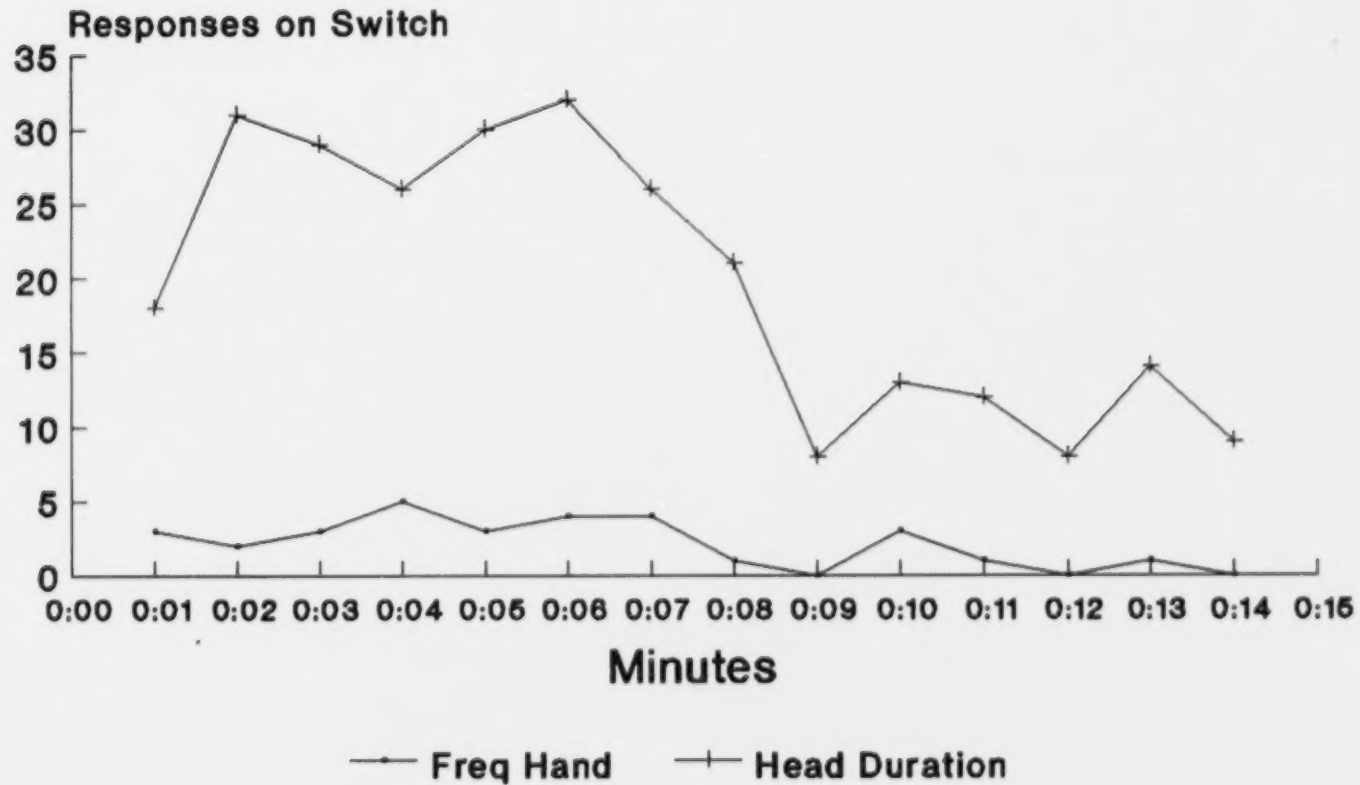
V Contingency 6/20

Press



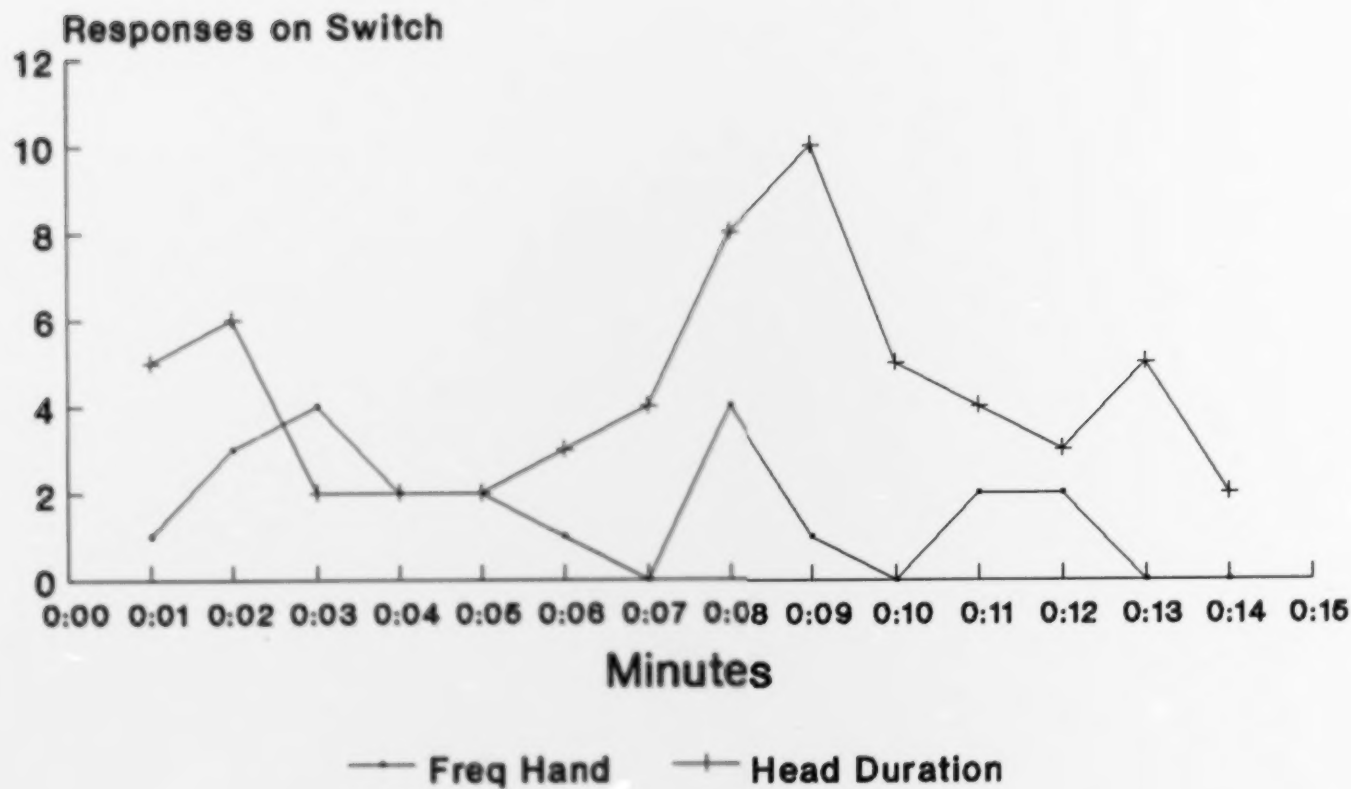
New Music for Head 7/11

Touch TV

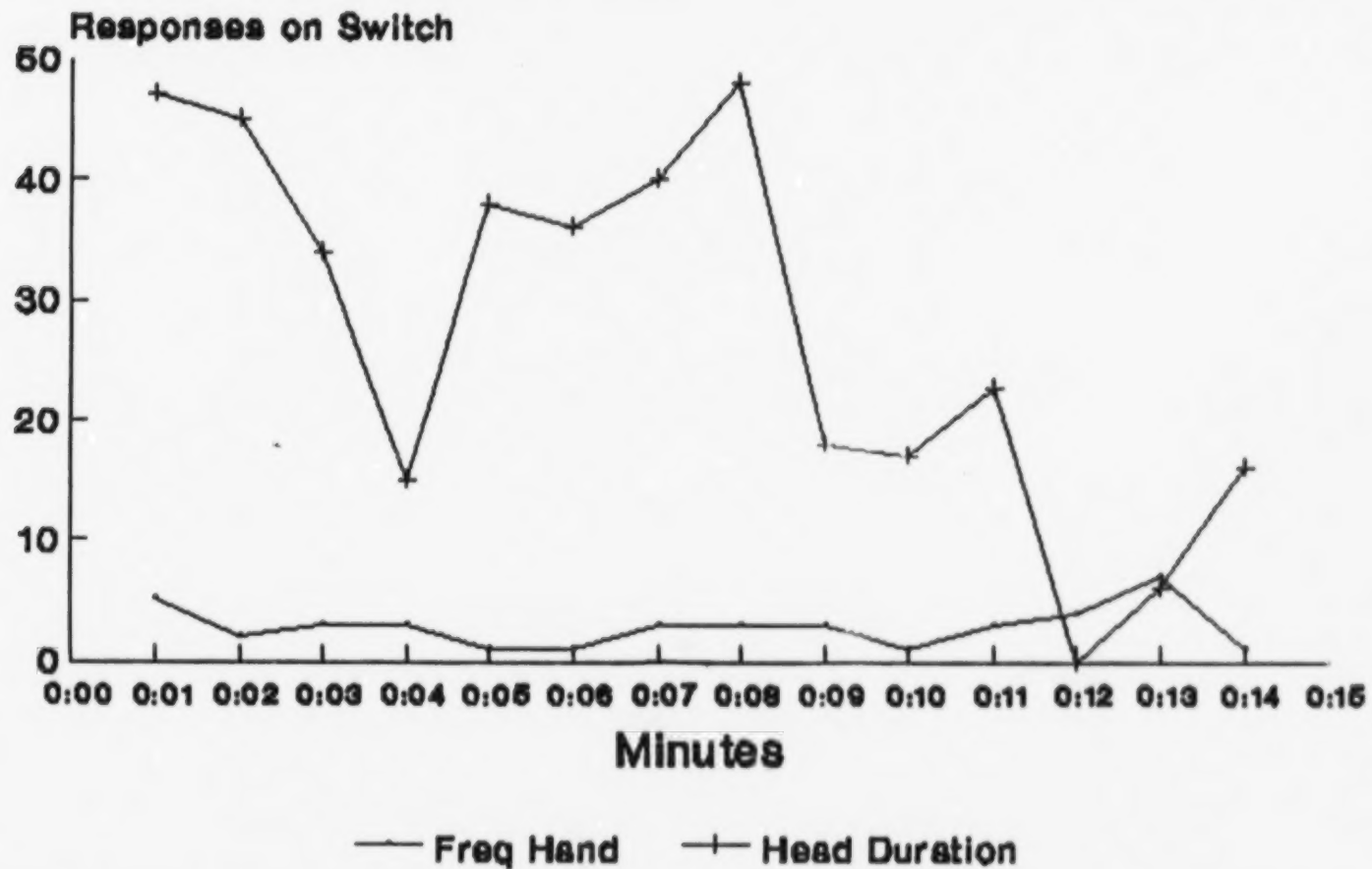


V Contingency Session 8/6

Bear

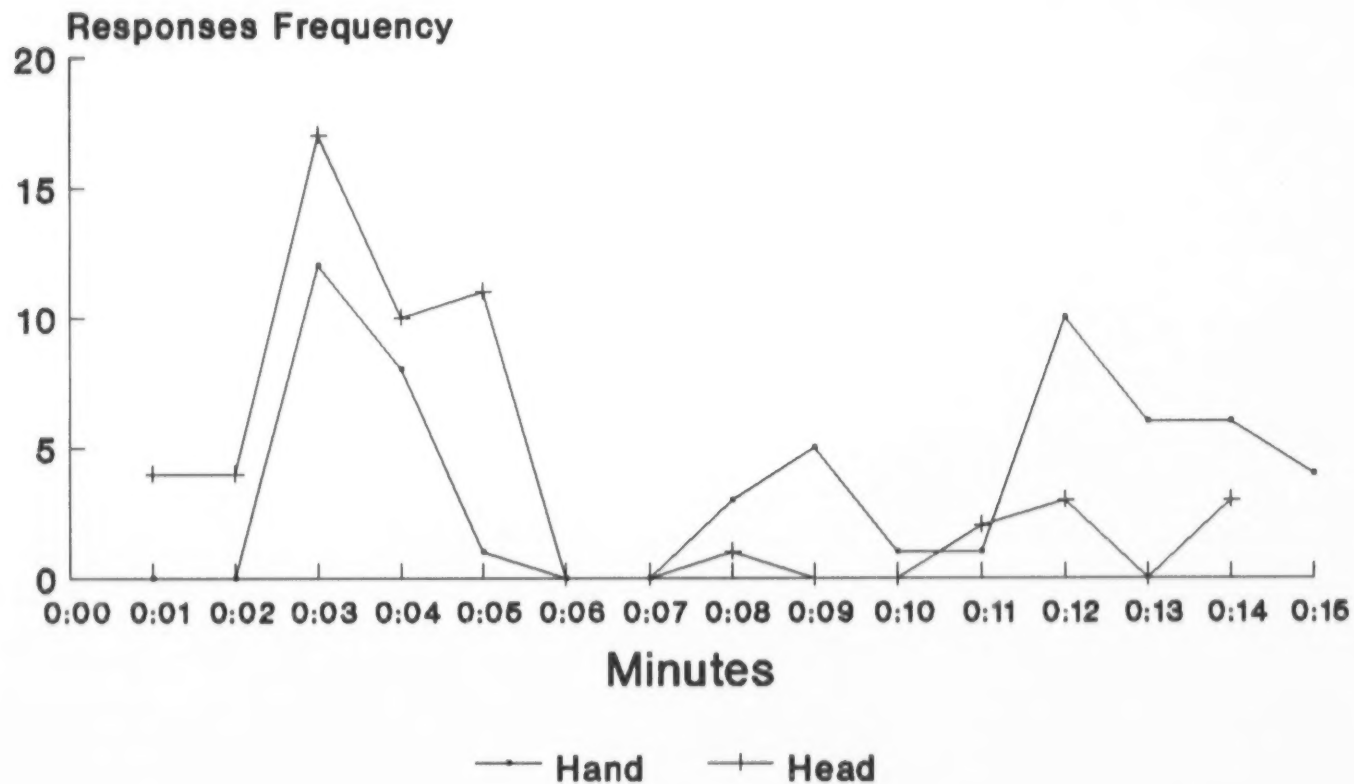


V Contingency Session 8/9



V Contingency Session 10/7

Hand Press Only/Single Toy



Toy Change Session 10/17

Hand/Tape, Music Box (< 8)

